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ABSTRACT

The booklet offers suggestions for parents concerned with providing lifetime protection for a child with mental retardation. Emphasis is placed on the interrelationship between the child's prospective needs of social and/or economic supports and the formal mechanisms which can be brought to bear on them. Four major topics are addressed: (1) guardianship (conservatorship, collective guardianship); (2) wills, trusts, and general estate planning (four basic estate plans, trustee selection, common trusts, importance of wills); (3) insurance benefits (the ARC plans, insurance for children, insurance planning); and (4) government benefits (the role of state government, federal programs of income support and health care coverage, interrelationship of government benefits and private income, Social Security benefits for adults, Medicare, Medicaid, Supplemental Security Income (SSI), and state utilizations of combinations of SSI and Medicaid options as they affect care of the disabled in the community). A list of recommended reading for parents and their attorneys concludes the booklet. (CL)

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*Suggestions for Parents Concerned with
Providing Lifetime Protection for a Child
with Mental Retardation*

PREPARED BY THE

ARC NATIONAL
INSURANCE AND BENEFITS COMMITTEE

ASSOCIATION FOR RETARDED CITIZENS

National Headquarters

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PREFACE

This booklet is designed to assist parents of persons who are handicapped by mental retardation to deal constructively with their concerns about the future. The fact that this edition is the fifth major revision since the first edition published in 1963 speaks to the dynamics of the age in which we live and to the higher aspirations we now have for people who are retarded.

Mental retardation manifests itself in many ways, some not always predictable, in the lives of those affected as those lives unfold. The child with mental retardation lags in learning and in social maturation but is protected as a child during minority; as an adult, he or she may be impaired to some degree in ability to earn a living or in ability to live as a socially self-sufficient person making important personal decisions, yet he or she has no automatic protections which recognize his or her special vulnerability. For some, disability may be so profound that dependence on others for sustenance and decision-making will be almost complete in adult life as well as in childhood, but, for most, adulthood is likely to be characterized by some degree of productivity, personal awareness, and capacity for self advocacy. Like others, all persons with mental retardation can be expected to grow and change with time in response to parental advocacy and professional help.

Providing the conditions which foster and support this growth and change in the more distant as well as in the immediate future requires planning – planning which recognizes that both the individuals with mental retardation and the circumstances of their lives will change. We live in a time of great social and economic uncertainty, but also of increased hope for persons with mental retardation.

In this booklet we have tried to show the interrelationship between the child's prospective needs for social and/or economic supports, as individually assessed, and the formal mechanisms which can be brought to bear on them – insurance, trust provisions, governmental benefits for the disabled and guardianship. State and federal laws which provide the basis for all these instrumentalities, along with private sector responses, continue to be in a state of flux. We report them as they are in early 1984, with the caveat that they will continue to change.

Perhaps the most important social circumstance affecting the futures of citizens with mental retardation in the eighties lies outside the scope of this booklet in the changing expectations of those futures brought about by new opportunities in education, in more optimistic outlooks for participation in the work force, and in new alternatives for enjoying less isolated lives, even for marriage in some instances. The social and economic protections which we as parents can and should put in place on behalf of each individual for whom we have parental concern must be capable of responding to these new developments as they occur in the years ahead.

In face of numerous demands on his time, Melvin D. Hecht, Esq., has devoted countless hours to rewriting the material on guardianship and wills and trusts in this as in previous editions. The Committee wishes to express its deep appreciation to Mel on behalf of all persons with mental retardation and their families.

This booklet in its various editions has been ARC/US's best seller. We sincerely hope that this new edition will continue this tradition; we welcome suggestions for the next revision.

ARC/US Insurance and Benefits Committee

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GUARDIANSHIP

Introduction

It is hoped that this section will assist parents in approaching the issue of guardianship for persons with mental retardation. It is not intended to tell or advise you that your child with mental retardation should or should not be placed under some form of guardianship. Some persons with mental retardation need guardianship and others do not. Some persons may not need guardianship at some point in their parent's lifetime but require it later. There are no easy answers, and there is no magic formula to determine when or whether guardianship is or is not appropriate.

Since guardianship of necessity results in either total or partial loss of rights and decision-making power for the person with mental retardation, that individual's abilities and needs must be paramount in the decision to seek guardianship or to find other less restrictive approaches to solving problems.

Thus, parents should ask themselves and others, "Why guardianship? Is it really necessary now? Is it being suggested only for the convenience of the service provider? Is there some other alternative to a court-supervised guardianship? Can we parents during our life, or can our non-retarded children or other relatives or individual trustees after our death continue to assist in making decisions for our child with mental retardation who is unable to make those decisions? Is there some compelling reason for guardianship and will guardianship solve the problem? For example, is there a real danger that my child will (a) run away and be totally incompetent to obtain food, clothing and shelter; (b) self-inflict injury or death; (c) be physically abused should they stay in their present living arrangements; (d) become involved in serious criminal activity; (e) be subject to frequent civil litigation for buying things beyond their means; (f) be forced into prostitution? Under the laws and hospital practices in our state, will the hospital provide emergency surgery and treatment without the informed consent of the person if a parent or other interested person consents? Under the law of

our state, can our child who desires to be sterilized secure this without a guardian being appointed and without a court order? Is it really in the best interest of our child with mental retardation that we seek guardianship?"

In other words, the only way parents can face the issue is to know what guardianship is, what it can and what it cannot do, whether or not it is really necessary and whether it is in the best interest of the individual with mental retardation. **Parents should learn the guardianship laws of their state and consult with other parents, their ARC and professionals in making this determination.**

What is Guardianship?

Guardianship is a court-approved legal relationship between a competent adult (guardian) and a minor child or handicapped adult (ward) which gives to the guardian the duty and right to act on behalf of the ward in making decisions affecting his life.

Total guardianship may also be known as guardianship or plenary guardianship. It gives the guardian power to provide complete supervision over an individual who lacks the ability to make decisions on his own behalf. Under this form of guardianship, certain legal rights of the person are totally removed. This involves a loss of the right to: (a) vote; (b) marry without permission; (c) contract (except for necessities); (d) choose a residence, program of education, training or employment; (e) sue or be sued in his own name; (f) consent to surgery or give legal consent on other matters; (g) buy and sell real estate or personal property; and (h) make a valid will.

For a person with mild mental retardation and for some persons with moderate mental retardation, the loss of all of those rights might be unthinkable unless there is a demonstrated need for protection which is substantially more important for the welfare of the person than the loss of such rights. On the other hand, the loss of such rights for individuals with profound and severe mental retardation may involve no real loss since they would not actually be exercising these rights, and their need for protection and supervision may be much more important for

their welfare than retention of legal capacity. In fact, a properly affirmative guardianship provides a means by which lapsed rights may be asserted.

Partial or Limited Guardianship - Conservatorship

Many states have developed or are developing partial or limited guardianship laws to protect the legal rights and interests of persons with mental retardation and to deny only certain rights and only after a specific determination that the person is incapable of exercising such specified rights. There is no judicial finding of total incompetence. The guardian is limited to act only in those areas in which the individual with mental retardation cannot act, and the individual retains the right to act in all others, thus preserving for the person with mental retardation as much freedom of choice, responsibility and independent decision-making as the person can manage.

In either total or limited guardianship, the probate court may appoint a guardian of the person or of the estate or both. Some states use the word "conservatorship" as meaning guardianship of the estate; in other states, it means guardianship of the person and the estate; in some states, it means limited or partial guardianship of the person and/or the estate. Some persons with mental retardation may need a guardianship or limited guardianship of the estate and not of the person. However, a guardianship of the estate can be avoided in some cases by use of a trust (see section on wills and trusts). Sometimes it may be advisable to have the same person act as guardian of the person and estate and at other times, it may be advisable to have two persons serving, one as guardian of the person and one as guardian of the estate, or possibly a bank trust department should serve as guardian of the financial interests.

Collective Guardianship

Several states have adopted collective guardianships provided by either public agencies or non-profit organizations to serve as guardians and to provide continuing personal interest in the child with mental retardation for life.

Public guardianship and public conservatorship (limited guardianship) have been part of Minnesota's laws. Under this plan, the probate court determines whether guardianship or conservatorship is needed and if needed, the type of supervision which is appropriate. The State Commissioner of Public Welfare assumes such guardianship functions and delegates the responsibility to the appropriate county welfare department social workers. The probate court receives a comprehensive social, medical and psychological evaluation before conducting a hearing. The proposed ward must be represented at the hearing by counsel. The person cannot be unduly medicated before the hearing and it may be held in the person's home in a relaxed atmosphere.

Under this plan, the person has the right to: (a) have the Commissioner prepare an individualized program to insure that therapeutic, habilitative, social, medical and dental needs are met; (b) receive an annual review of physical, mental and social adjustment and progress; (c) receive an annual review of legal status and have that status modified if necessary to reflect progress; (d) have the Commissioner exercise the supervisory powers in a manner which is least restrictive, conserving as many personal freedoms as possible; (e) obtain judicial review of decisions by the state guardian or state conservator when individuals or interested persons acting in their behalf disagrees with that decision; (f) be free of sterilization unless informed consent is given by the individuals, or if unable to give such consent legally, to have the court review whether it is in their best interest; and (g) to receive a full due-process hearing prior to placement in a state hospital (institution).

Under the Minnesota public guardianship laws, it is clear that the state has a legal duty, which can be enforced, to provide education, medical, dental and hospital care, maintenance and support for individuals during their lifetimes. In some other states, the public guardian is primarily an advocate and decision maker. There are, of course, advantages and disadvantages or real conflicts of interest in **any** form of guardianship.

Guardians Named by Parents' Will

Under the law of a number of states:

- Parents may appoint through their will an individual to serve as guardian for their minor children (under the age of 18). This is called a testamentary guardian. This tool may be used by all parents for all children, handicapped or not. The testamentary guardian would assume the powers and duties of the parent immediately upon the death of the surviving parent. This testamentary guardian can come into being only if both parents die before all their children reach the age of 18. This guardianship terminates for each child as the age of majority (18 years) is reached. At that time, however, a person who has been acting as guardian for a child with mental retardation during minority may petition the probate court (as may any interested person) for continued guardianship if it is determined by a thorough diagnostic evaluation that the individual needs continued guardianship.

If the parents incorporate a provision for a testamentary guardian in their wills and they survive the 18th birthday of their youngest child, the provisions will be nullified unless the parents direct that it continue in effect for their child who has been judicially determined to require a guardian.

- Parents who have already been appointed guardians over their child by a probate court may, through their will, name a testamentary guardian to assume (immediately upon the death of the survivor) the same powers and duties the parents were granted under the original guardianship order. It should be noted that such a provision in the will is not absolutely binding upon the probate court, but ordinarily, it will stand unless someone objects at the time the will is probated.
- If the parents should conclude that their child will continue to need a guardian for the foreseeable future, they might wish to consider utilizing the concept of a standby guardian. When a petition is filed for the appointment of a

guardian, plenary or partial, the petitioner (the person filing the petition) may also request that the court appoint a standby guardian. This practice is recognized in some but not all states.

The standby guardian, just as the word indicates, stands ready to assume guardianship when the original guardian dies or is incapacitated. If a standby guardian is appointed by the court, then the need for including a provision in the will for the appointment of a testamentary guardian is eliminated.

Some parents may feel that their child may not need a guardian while they are alive, but that some provision needs to be made in case of their deaths. This concern may be addressed in several ways. The parents may make a general statement in their will designating a person in whom they have confidence to assist their child immediately following their deaths.

The person would petition the court for consideration of guardianship if it appeared that the child's needs indicated such action. It should be remembered that a guardian will be able to do little more for the person with mental retardation during this transition period than a concerned relative or friend would do. It is quite likely that if your child has made it through life with your help and supervision without having a guardian, then they probably can continue in life without one, provided other help and guidance are continued. Securing support and care is the objective, and this can be generated without the restrictions imposed by guardianship. Again, however, it is possible that certain situations may arise after your death when a guardian may be necessary. Therefore, it would be wise to preplan by discussing this eventuality with a family member or friend. It is also quite possible that a trustee can appropriately fulfill many important needs which your child may have after your death. This will be discussed thoroughly in the next section entitled "Wills, Trusts and General Estate Planning."

How to Establish Guardianship

This will depend upon the law of the particular state. Under the law of some, but not all states, the following procedure is adopted. The probate court in the county of residence of the person has jurisdiction over guardianship proceedings. The petition and procedures for filing the petition may be obtained from the probate court. The petition may be filed by a parent or other interested party, usually through an attorney. The petition must be accompanied by certain diagnostic reports. After notice to all interested parties, a hearing will be held. If the court finds that the individual possesses the capacity to care for both person and property, the court may appoint a partial guardian. It is only when the court finds the individual totally without capacity to care for person or property that it may appoint a plenary guardian of the person, the estate or both. If a guardian is to have the power to apply for admission of the individual to an institution, it must be specifically authorized by the order of the court appointing the guardian or by a separate court order.

Conclusion

- Guardianship is not necessarily the simple solution to the problem of what will happen after your death. Before seeking guardianship, you should be satisfied that there is a compelling reason which is in the best interest and welfare of your child and that the advantages of guardianship clearly outweigh the disadvantages.
- Guardianship, when used properly, may be of real assistance to your child.
- Guardianship, when used improperly, may result in a total denial of the rights of persons with mental retardation, may impede their ability to make decisions for themselves which they can and should make and may greatly dehumanize them.
- Most parents are naturally concerned about protection for their children, but this form of security and protector-

ship can be secured in a number of ways without necessarily using the court-supervised formal guardianship.

- Sometimes an effectively drawn estate plan can eliminate the need for a legal guardian yet secure the same protection as a guardianship for your child (see the next section).
- Real security for your child lies in appropriate quality education, vocational rehabilitation training, financial assistance through SSI, Medicaid, Social Security and other governmental benefits, appropriate quality residential living arrangements, state and federal legislation protecting the rights of citizens with mental retardation, advocacy programs which reach out to monitor and secure services to provide for them the quality of life all citizens deserve.

Parents should play an important role in efforts to secure these objectives by membership and participation in and support of their local, state and national levels of the Association for Retarded Citizens.

WILLS, TRUSTS AND GENERAL ESTATE PLANNING

Introduction

This section assumes that the parents have a child who cannot manage money or property, or who cannot manage more than personal income, or who is vulnerable to having income or assets taken by unscrupulous persons or who will at some time require governmental financial assistance to pay for all or part of the basic costs of care.

This section is intended to serve as an introductory tool for the parents and their attorney to assist them in developing the most appropriate estate plan for their handicapped child and the other members of their family. Parents should plan their estate even when the financial picture is a limited one. Parents should consult with an attorney. If you do not have an attorney, or if you feel that your attorney is not well versed in the area of mental retardation, call your ARC for assistance in securing an attorney to help you in the development of an appropriate estate plan.

Parents are very much concerned about what will happen to their child when they are both deceased. They want to know: (1) how they can be reasonably certain that there will be a friend, advocate and protector of their child's legal rights for their entire lifetime; (2) how they can distribute their assets fairly among their children, whether normal or with mental retardation; and (3) how they can be reasonably certain that the assets which they leave for the benefit of their child with mental retardation will be appropriately expended, will provide for the child's entire lifetime and will not be taken by government or other creditors and will not make their child ineligible to receive governmental financial assistance such as Supplemental Security Income (SSI), Medicaid (medical assistance), etc.

Most attorneys who handle wills and estates are familiar with estate planning issues relating to federal and state income taxes, federal estate taxes, state inheritance taxes, federal and/or

state gift taxes but are less familiar with the special legislation and other considerations which affect persons with mental impairments. For this reason, our discussion in this pamphlet emphasizes the latter. However, this does not mean that the former should be overlooked. Consult your attorney!

Each Parent Should Have a Will

A will is a legal document which should be drafted by an attorney in which you specify how your estate or property is to be distributed among your surviving spouse, your children, other relatives, friends and charitable organizations. If you are competent, it can be revoked, amended or changed at any time during your lifetime and does not become effective until your death. Clauses of a will can provide for property distribution, for naming a guardian or, in some states a conservator or limited guardian, for creating a trust or for pouring over estate assets to a trust agreement. You should want a will even though you and your spouse own all of your assets in joint tenancy. The only exception may be if upon the death of both parents, their debts or liabilities exceed their assets, and even then, some parents may wish to nominate a guardian of the person and/or estate for the child.

If There is No Will

If you die without a will, your estate (property you own in your own name alone) is distributed to your heirs according to the laws of the state in which you live. The state makes a will for you if you have no valid will or no will at all. This law of intestacy was designed for normal family situations and not for families with members with mental retardation.

For example, under the intestacy laws of some states, when a person dies without a will leaving a husband or wife and children, two-thirds of the deceased's estate becomes the property of the surviving spouse. If there is only a child with mental retardation, that child would take two-thirds, and one-third would go to the surviving spouse – an obviously undesirable arrangement.

Under the typical intestacy law, when the second parent dies, all surviving children will share the family assets equally. This may be undesirable for the normal children who may be denied necessary funds for education or other needs while those same funds may be paying institutional or community residential charges for the child.

Also, if the person with mental retardation inherits any of the family's assets, a court appointed guardian of the estate of the person would administer the property under probate court supervision. All major payments would then be subject to the approval of the probate court.

Also, since the person with mental retardation or the person's guardian owns this property, it is subject to any claims made by the state for cost of care. Likewise, if the individual is receiving SSI or Medicaid or some other governmental financial assistance or benefits, that individual's right to receive these may be terminated until the property or resources are exhausted or spent down to a very nominal amount.

What this means is that without a will, there is little chance that the true intent of the parents will be carried out.

Review Your Wills Regularly

It is of great importance that you review your will periodically to determine whether it continues to reflect your wishes. Changes in your will may be required by the death of your spouse, changes in your economic condition, the progress of the child with mental retardation and the child's siblings, changes in the law relating to taxes, trusts, wills and governmental financial assistance.

Should I Leave Money or Property Directly to My Child With Mental Retardation?

There is no simple answer. Your estate plan will depend upon the size of your estate, the projected needs of you and your

spouse, the projected needs of all of your children, the age and nature of the handicap of your child with mental retardation, the availability of governmental benefits, the laws of the state where you live, etc.

In almost all cases, parents, grandparents and other relatives **should not** permit their child or relative who is mentally retarded to own or receive legal title to the parent's or relative's money, property or assets by will, inheritance or gift and should not make the person with mental retardation the beneficiary of any life insurance policy for the following reasons:

- Under the laws of most states, governmental agencies will take all but a very nominal amount of the assets owned by the person with mental retardation or by the guardian of their estate for the cost of care and services provided by the government to that person. (See section on governmental benefits.)
- If a person with mental retardation or that person's guardian owns assets in excess of a very limited amount, that person is disqualified from receiving certain important financial assistance benefits until the assets have been almost exhausted. (See section on governmental benefits.)
- Many persons with mental retardation are vulnerable to exploitation and are either totally incompetent to handle their own funds or incapable of managing more than their own earnings or nominal amounts of personal property or assets.
- Court-supervised guardianship of the estates of individuals with mental retardation may result in more rigid financial management than the parents or relatives desire.
- When a person with mental retardation dies intestate owning money or property, it will be distributed to the next of kin under state law, except that the state may file a lien for reimbursement of cost of care provided by the state during that individual's lifetime.

This does not mean that persons with mental retardation should not be encouraged and educated to learn about money and property and how to manage them. They should. We must remember that there are geniuses and "normal" persons who are spendthrifts and some persons with mental retardation who are excellent managers of their earnings and small amounts of assets.

Four Basic Estate Plans

There are four basic estate plans (with variations) which parents or relatives and their attorneys should consider.

- **Simple Will Which Excludes the Person With Mental Retardation.** Under this plan, each spouse executes a will which provides that their entire estate is to be distributed to the other spouse, if living, and if not living, then to the non-retarded children in equal shares, with the child with mental retardation specifically excluded from inheritance by the will. This type of will usually nominates a guardian of the person and estate of the minor children and an executor or personal representative. In some states, however, the validity of a provision disinheriting a dependent child may be challenged. Your attorney should advise whether or not a provision disinheriting a dependent child is valid in your state.

This plan may be advisable for young parents with very limited assets which would be required after their deaths for the maintenance of their other children. This plan will usually be changed to one of the other plans once their assets increase or the needs of their non-retarded children decrease. This plan may also be advisable for older parents with very limited assets who desire to distribute them to a non-retarded adult child who, they believe, will use them fairly for the sibling with mental retardation. Parents should be aware of the possibility that greed, mental illness, death or disability of the non-retarded child or their spouse may frustrate that intent.

● **Contingent Testamentary Trust Wills for Each Spouse.**

Under this plan, each will provides that the estate is to be distributed to the other spouse if living. Upon the death of the surviving spouse, the estate is to be divided into two parts; one part or fraction to be held in trust for the benefit of or distributed to the non-retarded children; and the other part or fraction to be held in a separate trust for the benefit of the child with mental retardation for life.

This trust for the child must be designed to protect the assets and income from the claims of creditors, including the state, and to prevent the person with mental retardation from becoming ineligible to receive SSI, Medicaid (medical assistance) and other governmental financial assistance benefits. It is designed to be primarily for the benefit of the person with mental retardation, to ensure that there will be a friend, advocate or protector of that individual's legal rights, to ensure that services that will be of assistance in developing maximum potential and in achieving a reasonable degree of normalcy and happiness, to supplement earnings and governmental benefits, if any, and not to pay for food, lodging, medical, dental and hospital expenses which could otherwise be claimed from another source.

This trust must therefore contain the following provisions:

- a. The trustees shall accumulate and add to principal the entire net income of the trust fund. (If the trustee cannot lawfully do so in your state, the trustees should be directed to pay the entire income to the non-retarded children or to pay to the child with mental retardation only that amount of income which will not cause ineligibility to receive governmental financial assistance benefits and to pay the balance to the non-retarded children or other designated beneficiaries.)
- b. The trustees shall have sole and absolute discretion to expend or not expend principal for the benefit of the person.

- c. The trust must contain the strongest possible spend-thrift trust provisions. This merely means that no creditor, including the state or any subdivision thereof, can secure the trust assets or income and that the person with mental retardation has no right to receive, demand, secure, give, assign, transfer, mortgage, borrow against or will the trust assets and income.
- d. Upon the death of the individual with mental retardation, the trustees must be directed to distribute the remaining principal and income of the trust to the other children, relatives or designated beneficiaries such as educational and charitable organizations, e.g., ARC.

Other Important Trust Provisions

- a. Empower the trustees at their discretion to expend the principal for needs not otherwise provided by government financial assistance and benefits or by the providers of services. Specify the needs as including spending money, additional food, clothing, health services not provided, radios, record players, television sets, camping, vacations, athletic contests, movies, trips and money to purchase appropriate gifts for relatives and friends. Suggest that the trustees periodically contact the individual, other relatives, the Association for Retarded Citizens and the staff of the residential facility as to what those needs might be.
- b. Provide that the trustees are under no obligation to expend principal for such needs, but that if they, in their sole discretion, do decide to do so, they shall under no circumstances pay or reimburse any amounts to the federal government, State of _____, to any other state or to any subdivision, or to any government agency for any purpose, including the care, support, maintenance and education of your child.
- c. Caution the trustees that in making any distribution to or for the benefit of your child, they consider the advisability of making such distribution in light of the amounts to which your child may be entitled from any

governmental agency, including but not limited to Social Security Administration benefits, Veterans Administration benefits, Medicaid (medical assistance) and Supplemental Security Income (SSI) benefits. Direct them to assist your child in obtaining these, but direct them to collect, expend, account separately all such governmental assistance benefits, **but not comingle** them with the trust fund. The same thing applies to the assets and income of your child with mental retardation.

- d. Provide that in the event it is determined by a court that the existence of the trust renders your child ineligible to receive SSI or Medicaid or similar governmental benefits, or if the trustees in their sole discretion determine that notwithstanding the Spendthrift Trust provisions, this trust may be subject to garnishment, attachment, execution or bankruptcy proceedings by a creditor of your child, the trustees shall terminate the trust and distribute the remaining principal and accrued income to your then surviving issue (other than your child with mental retardation) per stirpes. This provision is important because no lawyer can guarantee what the law may be in the future. If you include this provision, make certain that a co-trustee who is not a beneficiary of the trust makes the determination to terminate the trust. If a non-retarded beneficiary is a trustee and has the power to terminate, the income of the trust may be taxable to him. **Note: In some trusts, you may wish to include a modified termination provision or omit it.**
- e. Provide that the trustee or agent shall personally visit the individual's residence at least quarterly and preferably once or twice a month (if the trust fund can pay for such visits) to inspect living conditions, to inquire of the staff and especially of the person regarding treatment by the care provider; to let the individual know that there is a friend or advocate available for them; to see that there is spending money for things the individual desires; and to know that education, work training and social and recreational programs are being

received. Provision should be made for the payment of reasonable compensation to the trustee or agent for these visits, if possible, and for all expenses of travel, meals and lodging.

- f. Provide that the trustees or their agents shall make or have made an annual evaluation of your child including:
- Physical and dental examination by an independent physician and dentist.
 - Education and training program.
 - Work opportunity and earnings.
 - Recreation, leisure time and social needs.
 - Appropriateness of existing residential and program services.
 - Laws relating to various governmental financial assistance and benefits programs; unless the person has a reasonable chance of earning sufficient income for self-support, it is essential that these benefits be retained.
 - Legal rights including free public education, habilitation and treatment which meet constitutional minimal standards, a minimum or fair wage for work performed, privacy, the right to vote and freedom to marry.

The trustees or agents should base the annual evaluation on contacts with the individual, their brothers and sisters, the staff and volunteer members of the state and local ARC units.

This contingent testamentary trust plan offers great flexibility by permitting the surviving spouse during his or her lifetime to eliminate the trust or amend its provisions or to change the portion of the estate that will be held in trust for the benefit of the child. The ability to change is important, especially if the law, governmental programs and policy with respect to persons with mental retardation, the needs of the child or the trust laws

of the state change during the lifetime of the surviving spouse.

Consider using this plan if:

- The law of your state protects discretionary spend-thrift trusts against the claims of creditors.
 - Your estate and that of your spouse will not be subject to federal estate taxes or substantial state inheritance taxes.
 - Your surviving spouse is a good money and property manager.
 - You trust your surviving spouse to be fair to your children – both non-retarded and with mental retardation – and know that if the remaining parent remarries, steps will be taken prior thereto to protect the assets which you intend to be placed later in the trust for your child with mental retardation.
-
- **Wills and Revocable Living Trusts or Testamentary Trusts.** A trust is created either prior to the death of a specific parent (a living trust) or upon the death of the testator (a testamentary trust). The trust generally provides for the distribution of principal and income for the benefit of the surviving spouse during his or her lifetime. Upon the death of the surviving parent, a separate trust is established for the child with mental retardation. This plan may also incorporate an irrevocable life insurance trust. The trust provisions for the child with mental retardation under this plan should be the same as in the previous plan except that if the trust becomes effective during the life of the surviving spouse, the trustees should become empowered to expend principal to reimburse the surviving parent for the cost of care of the child, but only up to the amount which the living parent would be legally liable to pay the state or county for the care of the child. The reason for this provision is that under the law of many states, the parent is liable for part of the cost of care for a child under age 18 but not so liable for a child who reaches the age of majority.

Consider using this plan if:

- The law of your state protects discretionary spendthrift trusts against the claims of creditors. If your state does not, you should consult your attorney as to the feasibility of establishing a trust agreement in a state other than your own which does protect the assets and income of such a trust from the claims of creditors.
- Your estate or that of your spouse will be subject to federal estate taxes and/or substantial state inheritance tax.
- You are concerned about the ability of the surviving spouse to manage the estate during the spouse's lifetime.
- You are concerned that the surviving spouse would favor the non-retarded children to the detriment of the child with mental retardation, or vice-versa.
- You are concerned that remarriage of your surviving spouse might result in the elimination of any trust benefits for your child with mental retardation.

● Other Trust Plans

There are entirely different trust plans which parents can consider. A few parents may believe that the trust assets will be so large that the income and principal of the trust will pay all costs of care for their child's lifetime. Other parents may believe that the trustee should be **directed** and not be given discretion to expend the income and/or principal of the trust to supplement their child's own earnings, if any, regular Social Security (not SSI) and Medicare (not Medicaid) benefits for basic costs of care. Your child's eligibility for Social Security benefits is not affected by personal assets or unearned income or the trust. Also, eligibility for Medicare is not affected by personal or the trust's income and assets.

However, before parents decide to use trust plans other than discretionary spendthrift trust plans, they should consider the risk of rather rapid depletion of the

trust assets before the death of their child if creditors, including the state, can reach the income or principal of the trust, or if the child should lose eligibility to receive certain income tested governmental financial assistance benefits. For example, it is extremely difficult to predict for the entire lifetime: (1) what the future costs of foster or group home or institutional care may be, especially if inflationary trends continue; (2) what may be the amount of Social Security or Medicare benefits, or the eligibility requirements for same, or the periods of eligibility and ineligibility; (3) what may be the individual's state of health (it may be good today and sometime in the future, astronomical medical and hospital or long-term nursing home expenses which may not then be covered by Social Security and/or Medicare might be incurred); or (4) your own estates may be quite large today and much smaller upon the death of both parents.

Selecting a Trustee

It is obvious that great care should be given to the selection of trustees. The trustees in the above plans are given guardianship type powers and duties.

Provision should also be made that in the event a legal guardianship of the person or estate becomes necessary, the individual trustees and their successors should be so nominated. Thus, you may be able to eliminate a court supervised guardianship and its expense and avoid a court determination of incompetency where desirable.

A bank or corporate trustee should never be appointed as sole trustee. If the trust fund is sizeable, it may be desirable to appoint a corporate trustee and individual co-trustees, giving the individual trustee sole power to substitute another corporate trustee in order to keep its fees reasonable and its performance satisfactory. Before naming a corporate co-trustee, the amount of its annual fees and its willingness to accept the trust should be determined. Some banks will not accept a trust with a small corpus (under \$50,000 in some cases). Frequently, their annual fee is 6/10 of 1 % of the principal with a minimum of

\$300 to \$750 per year. There may be additional initial and termination fees which effectively preclude the use of a corporate co-trustee. Your ARC unit may be able to work out a satisfactory fee arrangement with one or more corporate trustees to serve as co-trustee without the duties of periodic personal contact.

It is frequently desirable to name two persons as individual co-trustees with named successors for each and with the power in each of the last named to appoint successors; or in the absence of such appointment, to name the Executive Director of your state or local ARC unit as trustee and give that person the power to appoint a successor. The trustee can locate some other person who can be a friend, advocate or protector for the person with mental retardation as well as manage the trust fund. This may be someone who is a parent or relative of another person with mental retardation who lives in the same facility as your child.

Frequently, one or more brothers or sisters will have a sincere love and interest in the welfare of their sibling with mental retardation. Parents should be advised of possible conflicts of interest when the trustee is also the person to receive the remainder of the trust upon the death of the child. In this situation, the parents should consider naming a son or daughter with another relative or friend, the latter not being a remainderman beneficiary of the trust. This combination is important if the individual trustee has the power to terminate the trust and make distribution prior to the death of the person with mental retardation. Otherwise, the non-retarded brother or sister trustee could be taxed on the income of the trust.

According to the law of your state, it may be possible to appoint your ARC unit as co-trustee. Your ARC unit usually understands the needs of persons with mental retardation in your community. It does not have to be a financial genius to manage conservative investments such as certificates of deposit, savings accounts, government bonds, etc. The trust instrument should spell out the specific powers and duties of the trustees - how and how not to act.

You should also determine whether the trust should be court supervised. (Some states mandate court supervision of testamentary trusts.) Consider the estimated size of the assets, the identify and reliability of the trustees and the cost of court supervision. You may desire to avoid court supervision of the named trustees and have such supervision beyond the named trustees, always providing that the trustees and the beneficiaries may request court supervision. This decision and the feasibility of bonding the trustee should be discussed with your attorney.

Although the handling of a trust costs money, the expense is likely to be no greater than the charge for a conservatorship or guardianship of the estate created by the probate court when there is no will.

Common Trusts

Since the cost of managing small trust funds is out of proportion to the amount of the assets, it is inefficient in such cases to go the trust route unless you have a personal trustee who will serve without compensation. To meet this problem, several state ARC units have worked out arrangements for a common fund which can receive assets (before or after the parents' deaths) to be used on behalf of the child with mental retardation. The costs of management are lowered by this pooling process. It may be worthwhile to inquire whether your state ARC unit has arranged for a common fund of this type.

Funding the Trust

The trust can be funded by any assets, including cash, stocks, bonds, real estate and life insurance. Proceeds from life insurance can be made payable to your estate or to your trust and this be controlled by the trustees under the provisions of the trust. Again, make certain that your child is not a beneficiary of your life insurance.

It should also be noted that the Association for Retarded Citizens, through the National Headquarters, has available to

its members an advantageous life insurance program for this purpose. (See section on insurance.)

Conclusion

- Each parent should have a will drafted by an attorney knowledgeable of the state's law of discretionary spendthrift trusts, the laws concerning SSI, Medicaid and other governmental benefits and federal and state tax laws.
- Review your estate plan regularly – at least every five years and earlier in case of death, disability or substantial changes in assets or law. Direct your trustees to check the law periodically and their management of the trust, if one be created, in order that trust funds will not be exhausted or used to disqualify your child from receiving needed governmental financial assistance, programs and services.
- Be certain that your child with mental retardation is not a beneficiary of your life insurance.
- In many states, a discretionary spendthrift trust such as described herein may be a most desirable plan since:
 - no one can compel the trustees to expend funds for the costs of basic care or to reimburse the government for such costs;
 - the income and assets of such a trust are not owned by or subject to the right of control by the person with mental retardation and therefore should not render ineligible to receive SSI, Medicaid and other income-tested governmental benefits;
 - the trustees can ensure that there is a friend, advocate or protector of individual rights and that programs and services to develop potential and achieve a reasonable degree of normalcy and happiness; and
 - the trustees can ensure that the trust fund will last throughout the individual's life by not utilizing it for basic costs of care such as food, lodging, medical, dental and hospital care but rather using it for those things which personal income and governmental financial assistance do not provide.

- In some states, the discretionary spendthrift trust is not valid against the claims of creditors. In those states, you must be certain that your will or trust agreement either excludes your child with mental retardation from receiving any distribution, or you should consider with your attorney the establishment of a trust agreement in a state which does protect the trust fund and its income against the claims of creditors.

You might also urge your state ARC unit to seek legislation similar to that passed by the Texas Legislature in 1977. See Ch. 294, Subchapter N, Section 61(g) which reads:

"For the purposes of this subchapter, no portion of the corpus or income of a trust or trusts, with an aggregate principal amount not to exceed \$50,000, of which a mentally retarded person is a beneficiary shall be considered to be the property of such mentally retarded person or his estate, and no portion of the corpus or income of such trust shall be liable for the support and maintenance of such mentally retarded person regardless of his age."

- Warn your parents and other relatives against leaving assets directly to your child with mental retardation by will or gift. Do not establish savings in your name in trust for your child.
- If you or your relatives have already established bank accounts, purchased bonds or stocks or placed other assets in the name of your child with mental retardation in amounts in excess of the eligibility requirements of SSI or Medicaid, it is suggested that you refer to the government benefit section which follows to determine the amount of assets your child can own and still maintain eligibility. Note again that eligibility for Social Security and Medicare is not affected by other income and assets. If your situation requires that the assets owned by your child be kept to a low level, consult with your attorney about ways to spend down such assets lawfully within such eligibility requirements. Consider spending the child's personal income and not your money for individual needs. Also consider having yourself appointed guardian or conservator

and then seek a court order reimbursing you for the reasonable expenses of maintaining your adult child in your home. You may thus be able to spend down such assets lawfully before your child needs to qualify for SSI or Medicaid to pay for group home or other expensive costs. Then you may later use your funds to create the trust for the benefit of your child.

INSURANCE BENEFITS

Life Insurance Is Essential

Every parent needs life insurance to provide for the support of the family's children in case the breadwinner(s) should meet with untimely death. This support will be needed in most families for only the temporary period until the children become self-supporting. However, for children, this period of required support will usually be longer, and in many cases, it will extend over the entire remaining lifetime of the child. Therefore, parents of children with mental retardation need extra amounts of life insurance.

Any life insurance plans you acquire necessarily depend on what other funds are available for your children, what other provisions you have made for them and any Last Will and Testament that you have drawn. All of these things are related and should receive careful consideration when making your insurance plans.

Naturally you want the largest amount of insurance that can be bought for the least amount of money. The younger the parent when the insurance program is begun, the better it is. It will be the quickest and least expensive way to set up an estate because the estate is established, for all practical purposes, as soon as the first payment is made on the insurance contract.

Because the life insurance field is a specialized one, it is mandatory to **obtain the advice of a good insurance counselor**. Tell the counselor your problem, give complete details of your particular situation and obtain suggestions from the individual on the best possible life insurance program for you. Inform the counselor of the life insurance plans available to you as a member of ARC/US, described hereafter.

Planning an Insurance Program

The amount of life insurance you should own depends on many variable factors. Although not all-inclusive, these are basic:

- your age, your earnings and the number of years you can anticipate having such earning power if you enjoy a normal life span;
- the number and ages of your dependents;
- the amount and kind of real and personal property you own and your dependents may own;
- the income and period of time you and your dependents may receive benefits from Social Security or other governmental programs;
- the manner in which you have arranged your estate, keeping in mind the impact of income, estate, gift and inheritance taxes; and
- your philosophy of life and living for yourself and your dependents, and your feeling of responsibility to your dependents, the community and society.

The first five factors can be accurately appraised by a qualified life underwriter working cooperatively with a trust officer and an attorney. It is important to remember, however, that any evaluation is subject to change. A periodic reappraisal is therefore essential.

ARC Life Plan

As stated above, the parents of persons with mental retardation need extra amounts of life insurance. The **ARC Life Plan** is a group life insurance program devised to give these parents an opportunity to purchase the needed extra amounts of life insurance at the lowest possible cost. This low cost is made possible by the mass purchasing power of the large membership of our Association.

This excellent plan is available to any member of a local or state unit of the Association for Retarded Citizens whose age is between 19 and 65. The member may apply for \$10,000 to \$100,000 of coverage to age 45. Up to \$80,000 is available to age 50, \$70,000 to age 55, and \$60,000 to age 60. The spouse of a member may also apply at the same time for \$5,000 of coverage; or if husband and wife are both members, each may apply for one of the above amounts between \$10,000 and \$100,000.

The cost depends upon the age of the insured at the time the premium is paid each year, and it increases beginning at age 30 every fifth year as the age of the insured increases. On page 27 is a chart showing the semi-annual cost for the various amounts of insurance for each age bracket.

Premiums can also be paid annually, semi-annually or quarterly. The annual premium is \$1.00 less than twice the semi-annual premium. The quarterly premium is \$0.50 more than one-half of the semi-annual premium.

The plan also provides other benefits and privileges. For example, if the insured becomes totally disabled prior to age 60 and remains disabled continuously for 9 months, the insurance will continue to age 70 (or to prior recovery) without payments of premiums. The plan also contains liberal provisions for converting part or all of the coverage to a permanent plan of insurance.

Every parent of a child with mental retardation should take advantage of the opportunity to participate in this attractive plan. Complete information may be obtained by telephoning the **Group Insurance Administrator** at **800/621-9903** [Illinois residents, (312)930-0020] or write them at **600 West Fulton, Chicago, Illinois 60606**, or contact your ARC unit.

Insure Your Child

Life insurance is an effective means of providing financial support after death for dependents whom the policy holder sup-

SCHEDULE OF CHARGES FOR ARC LIFE INSURANCE
DETERMINE INITIAL DEPOSIT FROM THIS TABLE - SEMI-ANNUAL CHARGE FOR INSURANCE

AGE GROUP	SPOUSE OPTION	\$5,000	\$10,000	\$20,000	\$30,000	\$40,000	\$50,000	\$60,000	\$70,000	\$80,000	\$90,000	\$100,000
Under 30		\$ 4.30	\$ 8.95	\$ 17.80	\$ 26.55	\$ 35.20	\$ 43.75	\$ 52.20	\$ 60.55	\$ 68.80	\$ 76.95	\$ 85.00
30 but under 35		4.75	9.85	19.60	29.25	38.80	48.25	57.60	66.85	76.00	85.05	94.00
35 but under 40		6.30	12.90	25.70	38.40	51.00	63.50	71.90	88.20	100.40	112.60	124.50
40 but under 45		9.10	18.50	36.90	55.20	73.49	91.50	109.60	127.40	145.20	162.90	180.50
45 but under 50		14.90	30.20	60.30	90.30	120.20	150.00	179.70	209.30	238.80	N/A	N/A
50 but under 55		25.05	50.40	100.70	150.90	201.00	251.00	300.50	350.70	N/A	N/A	N/A
55 but under 60		41.30	82.95	165.80	248.55	331.20	413.75	496.20	N/A	N/A	N/A	N/A
60 but under 65		67.80	136.00	271.90	407.70	543.40	679.00	N/A	N/A	N/A	N/A	N/A
		\$2,500	\$5,000	\$10,000	\$15,000	\$20,000	\$25,000					
65 but under 70		52.35	105.10	210.15	315.50	420.10	525.00					

ported during their life time. However, a citizen with mental retardation requires life insurance for many of the same reasons we all do ... there are always loved ones left behind the obligations to be met. These obligations are often left for the parents.

Since the ARC Security Plan is open to all members whose age is between 19 and 65, a person who needs life insurance and who is a member may apply for participation; however, the same health standards which are applied to other applicants will also be used in the case of an applicant with mental retardation.

ARC Security Plan

Not too long ago there was no sponsored life insurance program available to cover persons with mental retardation. The special **ARC Security Plan** fills this most needed service in our community with specially designed plans of \$2,500, \$5,000, \$7,500 and \$10,000 insurance coverage for citizens with mental retardation ages 2 through 65 as long as they are enrolled by age 50.

The Security Plan provides a favorable approach to establishing the cost of the program. Because of the widespread and increasing popularity of this innovative plan, coverage is offered at group rates. These are more economical than the traditional rates you would pay if other coverages was available.

The cost depends upon the age of the insured at the time the premium is paid each year, and it increases beginning at age 30 every fifth year as the age of the insured increases. See the chart below showing the semi-annual cost for the various amounts of insurance for each age bracket.

Every parent of a child with mental retardation should consider applying for this valuable special coverage offered through the efforts of your ARC. For further information, phone the **Group Insurance Administrator, 800/621-9903** [Illinois

residents, (312)930-0020] or write them at **600 West Fulton, Chicago, Illinois 60606** or contact your ARC unit.

Security Plan Rate Schedule - Annual Premiums*

Age of Insured	Plan I \$2,500	Plan II \$5,000	Plan III \$7,500
2 to 20	\$50.00	\$100.00	\$150.00
21 to 25	\$56.20	\$112.40	\$168.60
26 to 30	\$58.60	\$117.20	\$175.80
31 to 35	\$62.40	\$124.80	\$187.20
36 to 40	\$66.20	\$132.40	\$198.60
41 to 45**	\$72.40	\$144.80	\$217.20
46 to 50**	\$82.40	\$164.80	\$247.20
51 & Over	No further premium payment required		

Semi-annual premiums are 1/2 the amount shown plus 50

**Renewal only--A person cannot apply at age 45 or over
Rates increase when insured enters a new age category.

ARC Hospital Dollars Plan

Since many members have inquired as to how they can obtain hospital expense coverage for persons with mental retardation, the Association has worked very closely with our insurance administrator and developed a plan of supplemental in-hospital insurance - the ARC-endorsed **Hospital Dollars Plan**.

This plan is valuable and unique in that it has previously not been available, and unlike "traditional" hospital benefit plans, it provides coverage on all our members including those with mental retardation. Also, with today's spiraling medical costs, it is an excellent supplement for those members fortunate enough to have coverage in a group medical insurance plan.

GOVERNMENT BENEFITS

THE ROLE OF STATE GOVERNMENT

Despite all the attention that has been given recently (and will be given in this booklet) to federal programs of aid to disabled people, including people who have mental retardation, it remains true that, in law and under the U.S. Constitution, primary responsibility for assuring the well-being of vulnerable citizens lies with families and state governments. With the exception of basic income supports for certain individuals (embodied in Social Security and Supplemental Security Income programs for the aged and disabled), services such as residential care, protection in the community, habilitation, employment assistance and special health care are largely generated, or purchased, or otherwise mediated by state government agencies directly or through subsidy of the private sector. In some states, many of these responsibilities have been delegated under state law to county agencies. Increasingly, states and counties have drawn on federal aid, but if federal aid is not available, the state is still responsible under state law. For the parent who wishes to plan to reduce the future vulnerability of child, the first task is to know the resources of the state in which the person will reside as an adult. This is a good place to note the fact that just because an adult with mental retardation is physically present in a state does not necessarily mean that that person is legally domiciled there, and that state laws concerning residence may be at variance with federal rules governing residency under Medicaid.

Because states differ from one another so much, it is not possible in this booklet to describe state level resources in useful detail. Every state does have a state agency with special responsibility for people who, because of retardation, will be more or less dependent as adults. A parent planner is advised to confer with a local or regional representative of such an agency after reading the rest of this booklet. Be prepared to ask questions about SSI supplementation, residential alternatives, and Medicaid as they are implemented in your state.

FEDERAL PROGRAMS OF INCOME SUPPORT AND HEALTH CARE COVERAGE

In addition to or, in some cases, as an alternate to trusts and insurance plans which may be set up by parents, most persons with mental retardation are potentially eligible for benefits under Federal or state programs which come under the general heading of "social insurance" or, more broadly, "income maintenance." The term "income maintenance program" is an inclusive term for publicly administered programs such as Social Security, Supplemental Security Income, other public assistance, railroad retirement, veteran's benefits, retirement and survivor benefits for career military personnel, workmen's compensation, unemployment insurance and the like which are designed to cover the basic living expenses of persons who have been deprived of other usual sources of income as a result of retirement (after a certain age), disability, involuntary unemployment, or loss of support by a parent or spouse on whom the individual was dependent.

Generally speaking, these programs may be classified under the two headings of **insurance** and **assistance**. **Social insurance** programs give rise to entitlements based on the fact that someone (the "primary insured") has paid premiums, usually in the form of mandatory payroll deductions, into a public trust fund. In the case of Social Security, the individual or their dependents then become entitled to benefits when their employment is interrupted by death, disability or retirement, without regard to whether there are accumulated assets or unearned income from other sources. Thus, an unmarried adult son or daughter of any age who has been disabled since childhood can eventually become eligible for dependent's benefits under Social Security if the parent has (at death or retirement) attained insured status by working in covered employment and paying "FICA" taxes. In early 1984, an estimated \$1 billion was being paid annually to about 350 thousand adults under these provisions.

Public **assistance** programs, on the other hand, are supported by general tax revenues and are designed to assist needy persons. More specifically, the federally funded assistance programs are directed to three major categories of needy persons - those over 65; children who are "deprived of parental sup-

port;" and, those persons under 65 who are disabled or blind. In the case of disabled persons over 18, only the income and assets which they or their spouses have is considered in determining whether or not they are eligible for "Supplemental Security Income" (SSI). In the case of disabled minor children, parental income and assets which exceed a certain minimum are "deemed" available to the child and counted as if they were the child's own; however, the disabled child does not have to be "deprived of parental support" to qualify.

The programs of assistance to needy disabled adults, and to the aged and blind, which were administered by the states with Federal aid from 1950 to 1973 were replaced on January 2, 1974 by the Supplemental Security Income (SSI) program. It is administered by the Social Security Administration and is deliberately planned to complement Social Security for those with low benefits or none. Under SSI, nationwide minimum standards are applied. As a result, a larger number of adults disabled by mental retardation (as well as over 100,000 children) have become eligible for the first time.

More than 300,000 adults with mental retardation were receiving SSI benefits in 1983. In that year the federal share of such benefits reached an estimated \$1.5 billion. Both SSI and Social Security benefits are "indexed," that is, once started they increase automatically with inflation. In the remainder of this section any figure with an asterisk is subject to such an automatic increase.

These prospects have significance for families in all income brackets both immediately and in their planning for the future. It should be borne in mind, however, that despite increased "federalization" in the 70's, the state remains the principal arbiter of publicly supported programs for citizens with mental retardation.

In considering the significance of Social Security and SSI, related benefits should also be noted. For example, Social Security brings Medicare (after two years) for all disabled beneficiaries, and, in many states, new SSI recipients, as well as those receiving aid prior to January 2, 1974, are automatically eligible for medical assistance (Medicaid). The rational relationship between these four programs is shown in Diagram 1. SSI

recipients are also eligible for certain housing subsidies, and for a wide range of free social services. Careful planning to combine these different resources may permit an individual to live at home or in a supervised group home or apartment which is not classed as an institution but which provides some degree of guidance and protection, while also permitting some (insubstantial) gainful employment and increased community participation.



DIAGRAM 1: RELATIONSHIP OF SOCIAL SECURITY AND SUPPLEMENTAL SECURITY INCOME TO MEDICARE AND MEDICAID AS PARTS OF THE OVERALL "SAFETY NET"

Social Security and Medicare are federal programs and operate under the same rules in all parts of the United States; most people who receive Social Security because they are elderly or disabled are also entitled to **Medicare** although people who are disabled must wait two years for Medicare to start and elderly people (who are not disabled) are not eligible until they reach 65.

Supplemental Security Income (SSI) is a federal program which is in effect everywhere except in Puerto Rico and the territories. Most children and adults who receive SSI are eligible for **Medicaid**. The basic SSI program is administered by the Social Security Administration; states may choose to supplement the basic federal payment. **Medicaid** is administered separately by each state and the extent of coverage varies from state to state, but all states (except Arizona) pay for doctor's care and some hospitalization.

For more than two months, a person living in a "medical institution" which is certified for Medicaid (such as a skilled nursing home or intermediate care facility) may have their SSI reduced to \$25 a month when board and lodging is paid by **Medicaid** as part of care.

PLANNING AHEAD

The parent of today and the future advocate should both understand that, as this was written in early 1984, public programs were in a state of flux. In fact, Congress has made some changes in SSI almost every year since its inauguration in 1974. Major changes in Social Security were made in 1980 as well as 1983, and significant changes in Medicare are under consideration. Of great importance to persons disabled by mental retardation are the specific characteristics of the Medicaid program in their state of residence. The use of Medicaid to pay for services rendered to a person in various specialized living arrangements is discussed later.

Thus, current specifics may change, and in any case described later in this brochure, inter-state variations in both SSI supplementation (Title XVI) and Medicaid (Title XIX) can be significant. Therefore, the situation at any future time should be verified by consulting the local or state ARC, the district office of the Social Security Administration, and the state's social service or mental retardation agency or its local office. Do not expect your attorney to have this information.

Social Security is a good buy for any working person who has dependents, especially if one or more of the dependents is a person whose disability will prevent the individual from being self-supporting as an adult. Social Security is likely to remain a bargain in the future despite the prospect of further "reform." For this reason, and because you may want the information for planning purposes, it is desirable to check up on your earnings record from time to time. This will enable you to be sure that the taxes you or your employer have paid are properly credited to your Social Security. The Social Security Administration recommends that this be done about every six years; any District Office will supply a form for making this request.

The same advice can apply to your child's own work record. Sheltered workshop earnings (even if not "substantial") count for Social Security earnings purposes.

Do not underestimate the possibility that your child may become employed and have substantial earnings in the future.

Under these circumstances, a trust to augment earned income can be especially important, since ability to work may make the individual ineligible for government benefits based on your work record. Meanwhile, the individual is earning personal credits against retirement or future disability. People with mental retardation but can work should seek jobs with good fringe benefits, including health coverage and retirement.

Personal Information

The parent with foresight will, while planning, assemble records and information with which a surviving parent, guardian, caseworker or other advocate can move most expeditiously to secure future benefits; this includes information about benefits which are already being received.

The following information with respect to the person should be kept on hand:

- Social Security number (advisable to obtain now, if not already assigned; ask for form SS-5 at local Social Security office);
- Social Security numbers of both parents;
- telephone number of Social Security district office;
- marriage certificate of the parents if the child is a stepchild;
- birth certificate of the individual;
- guardianship papers, if any, including provisions for testamentary guardianship; any will in which the person with mental retardation is mentioned;
- papers concerning admission to any residential facility, past or present; history of school placement;
- names and addresses of doctors, clinics, schools, etc., holding records relative to the history of the retardation of the individual; name and phone number of current case manager, if any;
- record of any employment of the person; wages currently being received, including sheltered workshop earnings;

- last federal income tax return and W-2 statement of the parents (to show coverage under Social Security);
- veteran's 'C' number or discharge papers of parent;
- each parent's earnings record from SSA;
- information about present and future income and assets of the person including income from trusts and income and assets of the surviving parent if SSI is to be sought for a minor child;
- information about Social Security benefits and/or SSI if currently being received. Specifically, what is the basis for the SSI monthly payment being received in terms of "countable" and disregarded income, and the type of living arrangement (a copy of the most recent application form would be useful); and
- a copy of this booklet with relevant programs marked.

If the person is a resident in a facility providing some service to four or more persons, information should be recorded as to whether the facility is classified as a hospital, skilled nursing home, community residence (with the number of occupants), intermediate care facility, educational institution (see later), or other non-medical facility and whether it is public or private, profit or non-profit. The sponsor of such a facility or case manager will usually be knowledgeable about benefits and can assist in applying for same in addition to supplying medical records. Record the phone number of the social service worker, if available.

If the parent has been in employment covered by the Railroad Retirement Board or has been employed by the federal government, state government, or public school system, is a veteran or military retiree with a service connected disability, then additional or alternative survivorship provisions are likely to apply. Several major corporations now also provide significant survivors' benefits to adult disabled children. The parent is advised to secure basic data about these entitlements from their personnel office and to place them with the other items listed above. Include "where to apply" data. With respect to veterans' benefits, the American Legion Post

may be helpful as well as the Regional Office of the Veterans Administration. Service in the armed forces gives rise automatically to Social Security credits. Career military retirees should make sure that they are paying the supplementary contributions to the Survivor Benefit Plan to cover a child with mental retardation at any age under that system. The U.S. Railroad Retirement Board also has over 80 district offices (listed in the phone book). Its main office is **844 Rush Street, Chicago, Illinois 60611**.

Generally speaking, a dependent adult child who has been disabled since childhood will have the same benefits as a minor child under Social Security, Railroad Retirement, and veterans' programs; others should be verified. Also, a widowed mother who is actually caring for such a dependent adult child in the home may be entitled to mother's benefits even though she is not eligible for support as a widow. Usually a widow under 60 who is capable of entering the labor force does not receive benefits unless she has a dependent child in her care. (A widower may also receive benefits if the deceased mother was a breadwinner.)

THE INTERRELATIONSHIP OF GOVERNMENT BENEFITS AND PRIVATE INCOME

In planning ahead for a person with mental retardation, it is well to understand the circumstances under which the availability of private income or assets may influence eligibility for public assistance. Generally speaking, benefits under those programs which are based on the **insurance** principle (e.g., Social Security, Railroad Retirement) are not affected by the person's other income and assets. Those based on the **assistance** principle (e.g., SSI, Medicaid) will be reduced if the otherwise eligible applicant has significant personal income or assets, earned or unearned.

Generally speaking also, **entitlements** of dependents and survivors of veterans with service-connected disabilities (or death) are not related to the financial status of the beneficiary, while survivors of other veterans will receive **assistance** only if in financial need.

Most adults who will be eligible for SSI on the basis of disability in fact become eligible at age 18. Parents are advised to establish this entitlement at this time since it avoids some discontinuity at a time of crisis later on. Usually at least one parent is still working at the time the disabled child turns 18. If now, the now adult disabled child may already be eligible for Social Security on the record of one or both parents. The individual may then receive either a combination of SSI and Social Security, or Social Security only.

If it is not necessary to spend all of the benefit income for the immediate needs of the adult, a nest egg can be accumulated for future use. However, a cash accumulation in excess of \$1,500 will make the person ineligible for SSI benefits under present law. Again, Social Security is not affected by assets or other income.

The interrelationship of Social Security and SSI is complex and is likely to change over time with the individual's circumstances. About one-third of adult disabled child beneficiaries who receive Social Security also receive SSI.

Here are two examples:

- A disabled person who, as a result of training or rehabilitation, acquires the ability to be self-supporting may become ineligible for both SSI and Social Security as a **disabled** person but may, by working, develop personal Social Security coverage as a "worker." This can be activated later when the individual retires or becomes disabled again. A parent who foresees this possibility may wish to plan to augment the future wages or Social Security (which will be received by the child based on their own work) by providing trust income without expectation of calling on means tested assistance programs.
- An adult disabled child who now receives SSI and has no other personal income will experience a change when either working parent retires or dies, thus making the disabled adult eligible for some Social Security. SSI rules require this benefit to be applied for and counted; it may

thus reduce or even eliminate SSI. (At press time, legislation was pending which would permit the person eligible for Social Security to refuse it if receipt would be a disadvantage.) The child will almost surely receive **more** in Social Security after the death of a covered parent than during the retirement of that parent. The maximum receivable amount while the parent is alive is 50% of the parent's benefit (PIA). This can rise to 75% on the parent's death but quite possibly will not reach such a level as long as there are other family members who also receive benefits on the deceased parent's record.

The PIA figure can be requested by the parent through the Social Security Administration. For instructions, request a copy of **Estimating Your Social Security Retirement Check** from the nearest Social Security District Office. The PIA will depend on the extent of the parent's prior participation in the Social Security system. In the case where one parent has been in employment covered under Social Security and the other has been in another system (e.g., state employees' system), the combined PIA's should be considered in estimating benefits to a disabled child. Note that Railroad Retirement and Social Security have been partially integrated and are not additive.

It is important to take account of how things **will be** after your death. If you (or the child's other parent) have been steadily employed and made a good salary (in the high 30's or better in recent years), your child may well receive enough Social Security in the future to make dependence on SSI unnecessary and unlikely. You may therefore choose to augment Social Security benefits directly and plan fully to give the child as well as the guardian (if any) greater freedom in living arrangements than is usually possible to people who depend on SSI.

The person who receives Social Security but does not receive SSI (and even some who do in some states) may be eligible for Medicare (Title XVIII) but not Medicaid (Title XIX). Medicare covers acute care (hospital and physicians' services) but is less comprehensive when it comes to long term care. However, once the individual has spent an appropriate part of personal in-

come and resources for health care, that person may become eligible for Medicaid under the "spend down" provisions. To leave this option open, precautions should be taken (as indicated earlier) to assure that the principal of any trust is secure from invasion by or on behalf of the disabled adult.

All four programs (SSI, Social Security, Medicaid and Medicare) are described more fully later in this booklet.

Eligibility for Generic Benefits

Under Social Security, public assistance, and other programs cited above, regardless of whether the underlying principle is **insurance** or **assistance**, an individual may become eligible for benefits under circumstances which do not relate to retardation. For example, if a person is over 65 and has limited income and assets, that person will be eligible for nutrition programs for the elderly under the same conditions as any other needy senior citizens; similarly, a 12-year-old child whose father dies while insured under Social Security will be entitled to Social Security benefits until age 18 without a determination of the fact of retardation.

A surviving parent or other advocate for the person should make every effort to seek out and activate such entitlements. However, the ramifications are too numerous to permit coverage here. Discussion in this pamphlet will focus on those government benefits to which the person with mental retardation may become entitled as a result of **disability** or **handicap**. Also, we have not given great detail on the special rules affecting minor children, since in general such provisions, being short-term, do not greatly influence long-range planning in a way which differentiates the child with mental retardation from a normal child.

Definition of Disability - Ability to Work

For purposes of Social Security or Supplemental Security Income, disability is defined (for a person over 18) as: **inability to**

engage in any substantial gainful activity (SGA) by reason of a medically determinable physical or mental impairment. (The same definition is incorporated in the Railroad Retirement Act and the Housing and Community Development Act of 1974.) The condition must be such that it is expected to last at least 12 months or to result in death. However, it is not necessary that the person be completely unproductive. In fact, there are definite incentives in these programs for the individual to be as productive as possible. Under either program, it is presumed that the person is disabled if they cannot earn more than \$190 a month or are in sheltered employment (because they cannot enter competitive employment); ability to work is subject to further verification if earnings are over \$190 but under \$300 a month (SGA). If there is potential for becoming self-supporting, the person is expected to take advantage of vocational rehabilitation or similar services.

Refusal to accept rehabilitation services, if offered, can be cause for denial of benefits. On the other hand, benefits can continue during rehabilitation including a trial work period. Under certain circumstances a person who is working beyond "SGA" can retain Medicaid coverage. Ask your local rehabilitation agency or ARC for advice on "Section 1619(a) and (b)."

Within the limits of SGA, a disabled person may keep earnings without reducing Social Security benefits. The individual may even be able to retain higher earnings during a temporary trial work period under plan of vocational rehabilitation. With respect to SSI, the individual is allowed to retain \$65 of earned income (in addition to an initial \$20 of either earned or unearned income) without losing any SSI. Earnings above these levels generally give rise to a partial progressive reduction in SSI benefits. However, in the transition from dependence on SSI to wages, an SSI recipient can obtain a waiver on the income and assets limits if there is an SSA-approved Plan for Achieving Self Support (PASS). Thus, it is almost always more advantageous for a disabled person to work within their individual capacity than to remain idle.

Disabled Children Under Age 18

Disability in a child under 18 does not give rise to any special benefit under Social Security; however, it can occasion special benefits under Supplemental Security Income if the family meets the income tests or if the child is living elsewhere than with a parent. If a handicapped child is the dependent of a member of the armed services on active duty or of a deceased or disabled veteran, benefits in the form of special health or education services may also ensue.

For purposes of SSI, the definition of disability is derived from the adult definition – i.e., "a disability of comparable severity." There are certain clinical conditions which are presumed to be permanently disabling – Down's syndrome or frequent seizures, for example, or an I.Q. under 60. Higher scores call for further evaluation of work potential. Generally speaking, as applied to persons with mental retardation, the criteria of disability mean persons with moderate, severe or profound mental retardation will be found to be disabled, while for a person with an I.Q. between 60-69 inclusive, finding of disability will usually depend on the presence of additional complicating conditions or secondary handicaps. However, all cases are supposed to be examined on their individual merits and the total clinical picture.

Disability Determination and Review

In any case, under both Social Security and Supplemental Security Income, the final responsibility for determination of disability rests with the administering agency. The Social Security Administration has contracted with Disability Determination Services (DDS) in the states to carry out these determinations. The DDS is contacted on the applicant's behalf through the Social Security District Office where the applicant files. The DDS will review medical and other records provided by the applicant, but is not bound by professional opinion other than its own. It is important to supply as complete medical, psychological and educational information as possible in documented form – not just "opinions." Under the Adult

Disabled Child Program (described later), the evidence must show continuous disability originating before age 22; therefore, records covering diagnoses and special programming occurring at any age should be preserved for possible presentation at a later time. In any case, there can be subsequent periodic reviews of eligibility under these programs including review of disability status.

During the early 80s both the initial disability determinations and the reviews became more rigorous, and some people were unjustly denied or terminated. To prevent unfair denial, the initial application should be completed as fully and carefully as possible. A recent Wechsler test result is highly desirable unless the child or adult is very severely retarded. In case of denial or termination, the individual or their guardian or advocate should consider an appeal. Any appeal should be made in writing promptly. Follow the directions that come with the notice and contact the state protection and advocacy system or legal aid attorney right away. Where correspondence from SSA is customarily addressed to the person with mental retardation, it is especially important that an advocate be enlisted to help with a timely and appropriate response.

SOCIAL SECURITY BENEFITS FOR ADULTS

An adult who is disabled by mental retardation, or whose retardation together with some other impairment produces "disability" may receive Social Security benefits in one of the following ways:

- on earnings records after the individual has attained insured status as a worker; or
- on the earnings record of **either** parent, the parent having died, retired, or personally become disabled after attaining insured status.

The benefits are not additive, but the individual may claim the highest benefit available at a given time under either of the possibilities. For example, if the father becomes disabled at an early age and benefits are paid to the disabled child while the

mother continues to work, it may turn out that the benefits on the mother's record will eventually be the higher.

Disabled Worker Benefits

The disabled worker must have attained insured status for disability benefits. For a worker under 31, this requires at least two quarters of coverage for each year since age 21 but not less than six quarters; for a person between 31 and 62, it requires one quarter for each year over age 21 but not less than twenty quarters within the latest ten-year period, subject to a maximum of forty in all. In either case, there is usually a five-month waiting period between the time of eligibility and the beginning of benefits based on disability.

"Coverage" implies that the individual has covered earnings on which Social Security taxes have been paid by both the individual and the employer. In 1984, one quarter of coverage is credited if earnings in the year reached \$390*, two quarters for \$780, and so forth up to four. The minimum amount necessary for one quarter of credit rises each year as average wages rise. Under these conditions, it may be possible but not easy for a person who is already disabled to work enough to become covered and eventually "insured" as defined above.

Under these rather restricted circumstances, some young adults who work in sheltered workshops are able to meet the minimum coverage requirements by the time they are 23, at which point they could claim and receive disabled worker benefits, usually at the minimum rate. Since such an individual generally continues to work in the workshop (earning less than \$300 a month), Social Security taxes continue to be paid while benefits are being received, just like older people who work beyond age 65. The benefit level is frozen at a very low level except that it will be subject to cost of living increases. Under these circumstances, the person may also be eligible for SSI at the same time.

Of course, by earning more than just enough to claim four quarters in a year, one increases one's average monthly earnings and thus raises one's eventual benefit well above the minimum. This applies to all workers, whether disabled or not.

For example, a person who works regularly earning a federal minimum wage will eventually become entitled to a personal Social Security benefit which exceeds the federal SSI limit by about 10%. The strategy of a parent who foresees this outcome may well be to augment the child's income through trust income.

Adult Disabled Child Benefits

An adult who has been continuously disabled since before age 22 and who remains unmarried may receive Social Security benefits as the dependent of an insured parent when that parent retires, dies or becomes disabled. This benefit becomes available even if the person has been living away from home and receiving support from others, in foster care or in an institution. "Parent" includes adoptive and step-parents. The amount of benefits can (after the death of the insured parent) be as high as 75% of the insured parent's primary insurance amount (PIA). This, in turn, depends on the insured parent's average covered earnings as well as the number of other family members who are also entitled to draw on the parent's account. A person who has been fully covered as a worker under Social Security between 1971 and 1981 during each of which years there was earned income at least equal to the maximum on which FICA taxes were levied at the time and who retired at 65 in 1984 could anticipate a PIA in the neighborhood of \$700* a month. This could result in a monthly benefit of over \$500* for the disabled survivor child. (Under a 1974 law, the PIA for future retirees under Railroad Retirement is set at 130% of Social Security PIA.) The PIA is fixed at the time of first entitlement, but benefits based on it are subject to cost of living increments. It is estimated that by 1994 the maximum disabled child's benefit will increase to over \$900.

The amount for the child may be reduced if there are other beneficiaries drawing on the same account. This is a result of the limit on maximum family benefits (MFB). Under the MFB rule, the worker always receives a full share, but the remainder allowed to the family is pro-rated. For example, if MFB is 175% of PIA, the worker parent receives 100% of PIA while entitled spouse and one disabled child each receive 37½% of PIA. On

death of the worker, the widow(er) is entitled to 100% of PIA and the child to 75% and neither is reduced. On the other hand, if there are more than two survivors, reductions will occur. If children are entitled on the record of two parents, the MFBs are combined to form a "super maximum."

MEDICARE

Individuals who receive Social Security benefits on account of disability will be covered for Medicare after they have been receiving benefits for two years. A booklet, **Your Medicare Handbook**, can be obtained from the District Social Security Office. Long-term care and private duty nursing are not covered, but some home health care and comprehensive outpatient rehabilitation facility services are covered, as well as hospitalization for up to 90 days. Physicians' services are covered under "Part B" for which a premium is charged by deducting it from the Social Security benefit checks (see "Payments of SSI and Social Security").

Social Security and Medicare are entitlements which do not depend on where the individual resides except that prisoners lose their entitlement. Therefore, residents in all types of facilities except prisons can receive Social Security benefits and covered medical services covered by Medicare. Social Security can also be paid to persons who live in other countries.

Railroad employees and retirees should be sure that their Medicare premiums are being paid to protect their own and their dependents' coverage.

If the individual is eligible for Medicare but not Medicaid, it may be possible to obtain private supplemental insurance to cover the deductibles and co-insurance not picked up by Medicare. Such auxiliary coverage for both aged and disabled beneficiaries is widely available from Blue Cross-Blue Shield, but there are limited open enrollment periods. (Do not be deterred if the form Blue Cross asks you to fill out refers to persons over 65. Disabled Social Security beneficiaries are entitled to the same supplementary Medicare coverages as the elderly.) Medicare pays 80% of the "reasonable" costs for physician's services. If the provider charges more than 100% of that cost, the excess is the patient's responsibility.

SUPPLEMENTAL SECURITY INCOME

SSI is important in future planning for families who do anticipate that the amount of Social Security payable to their surviving child with mental retardation will not exceed the basic Supplemental Security Income benefit. About half the children of retirees are dually entitled but less than a third of adult disabled children who receive benefits as survivors also receive SSI. Usually, SSI can be started for the young adult while parents are still active and employed, since the individual is not yet receiving Social Security and parental income and resources are "deemed" to the child only until he reaches 18. Later, if the disabled adult begins receiving Social Security, SSI will be reduced or terminated.

Income

The basic SSI benefit from federal sources for an individual in 1984 was \$314* a month; in many states a state supplement increases the total amount received. If the disabled individual has \$20 or more of other unearned income such as Social Security, trust income, interest on savings, and so on, the SSI payment will be adjusted to make the total income up to \$334* plus the applicable state supplement whatever that may be (see section on Medicaid). Certain types of "in-kind" income may be counted also. For example, if a relative pays taxes or bills on behalf of a disabled person, their value is counted; if the SSI recipient lives in the "household of another" and does not pay for maintenance, the benefit will be reduced by one-third of the federal portion.

Assets

No SSI benefits are payable to an individual who has countable assets (such as securities, jewelry, real estate or a savings account) exceeding \$1,500 in value. Certain non-cash assets are not taken into account, however, in determining eligibility - such as a car for one's own use and the house in which one lives.

At first these may seem of little importance to a person with mental retardation who cannot manage such responsibilities. However, the "house" rule extends to contingent or joint interest in a house, condominium or co-op apartment used as recipient's own residence. Since living in such a unit cannot be called "living in the household of another" (see above), there may be some merit in exploring this option for some adults. In fact, several successful community living arrangements have been capitalized by parents who each bought an "interest" and gave it to a disabled child.

State supplementation of SSI is in effect in most states. State plans vary. Different supplements are payable in recognition of different living arrangements. The federal government administers these supplements in some states but not in others (see section on Medicaid). However, most Social Security Offices have leaflets which describe briefly the combination of federal and state benefits available in that state under SSI. An up-to-date copy should be requested whenever planning or implementation is under way for an eligible individual.

The following will indicate how living arrangements affect SSI for adults:

- **Medical institutions:** an eligible person who is in a hospital, nursing home or intermediate care facility – including an "intermediate care facility for the retarded" (ICF/MR) – whether public or private, where the bills are paid on the person's behalf by Medicaid will have the SSI reduced to \$25 a month. This "personal needs allowance" (PNA) is intended for incidental spending by the individual. The recipients basic maintenance is assumed as part of the cost of "in-patient" care under Medicaid. (This \$25 amount is payable as federal SSI if the patient has no more than \$20 in other income. Some states supplement the PNA to [say] \$35 a month.)
- **Public institutions other than "medical" institutions:** generally speaking, otherwise eligible disabled persons do not receive SSI unless the institution in which they live is classified as: (a) an educational or vocational school (for

which there is a restricted definition); or (b) a community residence for 16 or fewer persons.

- **Living "in the household of another" who provides both board and lodging in-kind:** In the prototype case, there is one-third reduction in SSI. This does not apply where the beneficiary pays the pro-rata share of the costs. It also does not apply in private group homes or foster placements arranged as part of a program administered by a public agency. In these cases, full federal SSI is paid, usually supplemented by the state up to the actual cost.
- **Non-public, non-medical care facilities, or public community residences for 16 or less:** Some 35 states have taken advantage of their option under SSI to designate such facilities and to authorize a state supplement to SSI for eligible persons living in them. The supplement usually exceeds the benefit for "living alone." The maximum allowable supplement payment varies by state, but in 1983 was close to \$600 a month in at least one state, making the total SSI available over \$900 a month. Several states, e.g., Montana, New Jersey, New York and Wisconsin, have designated a special category of non-Medicaid facility for persons who have mental retardation and/or are emotionally disturbed under this option.
- **Living with spouse:** If the spouse is ineligible, income is deemed available to the pair. If they are both eligible, their combined benefits amount to 150% of an individual benefit. (There are additional rules applicable to this situation which can be readily learned from pamphlets available from Social Security District Offices.)

MEDICAID

Social Security and Medicare, as well as the basic federal SSI payment, are administered under uniform rules throughout the country. In contrast, SSI supplements and Medicaid are peculiar to each state.

Medicaid, authorized under Title XIX of the Social Security Act, is composed of a set of 51 different, federally-aided, state-

initiated and state-operated programs designed to assure that certain eligible individuals with low income and very limited resources can receive basic health care and other health related services for which the provider ("vendor") will be paid by the state. Payment for such care is called "medical assistance."

Each state designs its own Medicaid program within certain federal guidelines and requirements. There is substantial variation among the states in: (1) eligibility requirements; (2) range of services offered; (3) limitations imposed on such services; and (4) reimbursement policy (how much the vendor will be paid). No state is required to have a Medicaid program, and in fact, Arizona did not have one until 1982. What follows applies to the states and the District of Columbia. Medicaid is also available in Puerto Rico, the Virgin Islands, Guam and other territories under somewhat different rules.

Populations Eligible Under State Medicaid Plans - Disability

Under the federal rules, if the state wishes to have "federal financial participation" (FFP) in its medical assistance program, it must present a detailed state plan. The plan specifies: (1) the eligible population; and (2) the types of services which will be paid. There are mandatory populations and services plus options in each category.

At a minimum, this plan must cover certain recipients of public assistance, specifically recipients under the basic federally aided program of Aid to Families with Dependent Children (AFDC) and most recipients under the federal Supplemental Security Income (SSI) program described earlier. All recipients of federal SSI are eligible in 35 states and the District of Columbia. In addition, states can (and some do) cover persons who receive "state supplements" up to the limit set by the state itself, and also the "medically needy," i.e., those not eligible for cash assistance but who need help paying medical bills. This option is also circumscribed by law and regulation. As described earlier, it is common for a state to pay special supplement for a disabled person who resides in a "non-medical facility." Such a supplement may increase the income eligibility level for Medicaid for persons in these facilities.

The state plan also must set forth "the amount, duration and scope" of services for which that state will pay. The "mandatory" services which a participating state **must** provide to those persons whom the plan **must** cover are: in-patient and out-patient hospital care; laboratory and x-ray services; skilled nursing care for adults; screening, diagnosis and treatment of children; family planning services; and physicians' services. However, the plan may severely limit the **amount** of service it will pay for - the number of hospital days, for example. If you plan to rely on Medicaid as a future resource for your child, you would be well advised to study the practices of your state in respect both mandatory and "optional" services.

States can elect to cover a wide range of optional health care services. All states except Wyoming and Arizona have opted to include "intermediate care facility services for the mentally retarded." These residential facilities must meet special standards designed to address the developmental needs of children and younger adults. Some states cover costs in both public and private, large and small ICFs, but others limit ICF/MR beds to those in publicly operated facilities. The fact that a person is not Medicaid eligible does not preclude admission to an ICF/MR if there is an alternate means to pay, or if the state chooses to serve the individual without claiming federal reimbursement.

As of 1984, all but a small fraction of the beds in state operated facilities for the retarded were certified as "ICF/MR." However, the population of such public facilities has been reduced by almost 40% in the past ten years and further reduction is expected. Some are being closed. People who would have been admitted in, say, 1965, are now more likely to be living in smaller private facilities closer to home; some of these small facilities are operated under ICF/MR programs. Others are "non-medical."

Many of the "supportive services" needed by developmentally disabled people "in the community" are not included among services (optional or mandatory) usually covered by Medicaid outside institutions, and until the enactment of the "community care waiver" (Section 1915(c)), there was no way to invoke federal assistance in paying for them. This waiver was of limited applicability, however, and in 1984 ARC/US was

seeking a more dependable and widely applicable system which would nevertheless be less costly than ICF/MR care, on a per capita basis. The potential of Medicaid for offering stable, ongoing funding for needed services in the community is considerable if it can be extended to cover some "social" support services such as supervision within a community residence, personal care, respite care, or needed specialized recreation, for example. If such services can be covered under Medicaid, the basic food and shelter costs can usually be covered by Social Security or SSI, with reasonable state supplementation.

The state also can exercise some options for covering people who are disabled but do not receive SSI. For example, at the option of the state, people who qualify either as aged or disabled, as defined under SSI, but whose gross income, including SSI, is too high but does not exceed three times the basic federal SSI standard, less \$20, may be covered under certain circumstances. As mentioned earlier, this federal SSI standard was \$314* for an individual living alone in 1984. In many states, the "special income standard" (limited to \$882* per month in 1984) is applicable to persons in institutional care but not to persons who do not reside in long-term Medicaid certified institutions such as skilled nursing homes (SNF) and intermediate care facilities (ICF or ICR/MR).

While residing in such an institution, the individual's federal SSI payment is reduced to \$25 a month "personal needs allowance." If the individual has Social Security or other income of more than \$45 a month, no SSI is payable but Medicaid pays for those costs of personal care which exceed income.

In 1984, it was possible for a worker who was retired on age or disability to have an income from Social Security ranging from about \$100 up to about \$800 a month. (In the case of an adult disabled child, the upper limit was about \$525.) Such a person is eligible for Medicare after being on Social Security for two years. Although Medicare does cover "home health services," it does not provide extended long-term care in institutions or out. Thus, a person receiving substantial Social Security benefits could be in the position of being eligible for Medicaid only if a resident of a long-term care institution, where the "special income standard" applies. (In this case, most of the

Social Security will be used to pay for part of the cost of the institutional care while Medicaid pays the rest.) This may, in fact, be the only way in which the individual can receive the maintenance therapies and social support services required by the individual's condition, whether the impairments are physical or mental. The ARC/US is seeking to change this bias toward institutional care either by making the "special" standard applicable for people who live in the community or by some other reasonable provision. You may check with the ARC to determine what change, if any, may be in effect in your state at the time you read this.

A final caveat is in order about the stability of Medicaid programs. In general, sudden drastic changes are unlikely but during the severe recession of 1981-82, a number of states cut back on Medicaid coverage, and Congress relaxed some of the mandates. Both Medicaid and Medicare are targets for reduction by those who seek to reduce the federal deficit.

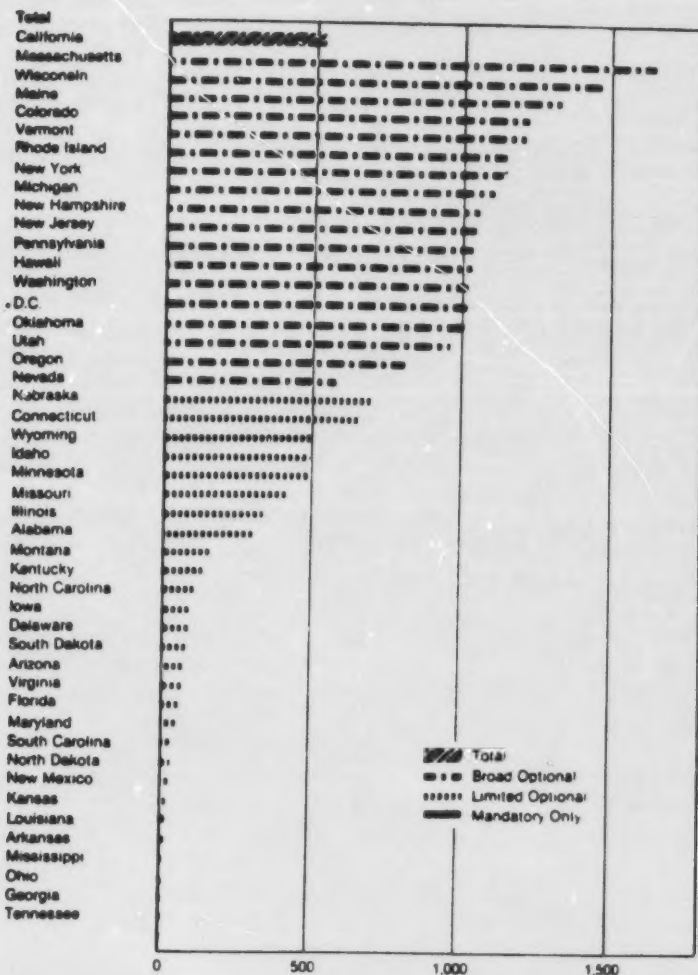
STATE UTILIZATIONS OF COMBINATIONS OF SSI AND MEDICAID OPTIONS AS THEY AFFECT CARE OF DISABLED IN THE COMMUNITY

The strong interaction between state options under the SSI program and the state options under the Medicaid program deserves to be examined in some detail. The variations in state supplementation are illustrated in Chart I.

All states except Texas and West Virginia have some forms of state supplementation for SSI. How a state defines the income limits for supplementation of its SSI population has much to do with its use of Medicaid. States have the option of including all SSI recipients (or eligibles), as "categorically needy," under their Medicaid plans or of using a less liberal standard based on the income and resource levels which they had in place in 1972 before SSI. Fourteen states use the 1972 standard. This means that some SSI recipients do not have Medicaid coverage in those states. On the other hand, states may make eligible for Medicaid persons whose income disqualifies them

Chart I

Number of persons receiving State supplementation per 1,000 Federal SSI recipients, December 1981



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for federal SSI but who receive a "state supplement only." As the chart shows, about one-third of the states use state supplementation quite liberally. California has 62% of all the "state supplement only" SSI recipients. They are also eligible for "Medi-Cal."

Other Options

States also differ in their use of other options available to them under SSI optional supplementation rules. States can choose to have their supplements administered by the Social Security Administration in conjunction with the monthly payouts of federal SSI. In this case, the recipient receives a single monthly federal check, which is gold in color. Such states may offer several different levels of supplementation. These can vary by geographical area (reflecting different costs of living), by living arrangement (one or more types of accommodations such as a group home), or by age or category, for example, "blind children." (If the state administers its own supplements, it can more freely adjust the classes of income to be disregarded, assets tests, etc., but must bear the cost of administration.) As many as 33 states make use of the options under SSI which permit supplements to be paid to cover costs of board and lodging and some service in an approved type of "non-medical" living arrangement. In addition, these people are covered by Medicaid for doctor's care, hospitalization, etc., according to the state plan.

Alternatively, a state may administer its own "special needs" assistance in a still more prescriptive way. Such assistance "based on need" is not "countable income" to the SSI recipient; 31 states formally list such "special needs" provisions, although in 11 the aid is emergency or short-term only.

A state may use its Medicaid mechanism to pay for services to persons who are not eligible under the federal Title XIX rules, provided the state does not claim federal reimbursement for that particular payment.

How SSI and Social Security Benefits, Medicaid and Medicare are Paid

SSI and Social Security benefits are individual entitlements and must be paid to the individual or to his "representative payee." They do not belong to the family nor to any provider. Medicaid and social services costs, by contrast, are usually paid by the state directly to the provider (vendor). Medicare payments are sometimes paid to the vendor (as in the case of hospitals and home health agencies) and sometimes as reimbursement to the individual on proof of billing by a physician or other covered provider.

SSI checks may or may not include the state supplement depending on whether the state has opted for federal administration. If it does not, there may be a separate state supplement check. If the individual is entitled to both Social Security and SSI, he will receive two federal checks, the former green and the latter gold in color. There are penalties for accepting checks in excess of that to which one is entitled. Guardians and payees should consult the Social Security District Office if in doubt. Recipients or their payees under SSI are responsible for reporting changes in income, assets and work status.

Representative Payees

If, in the opinion of the Social Security staff verified by a physician's statement, the individual is not able to manage personal SSI or Social Security benefits, the Social Security Administration (or Railroad Retirement Board, as the case may be) will appoint a "representative payee." An individual who is serving as guardian of the person will usually be given preference in this appointment, but they must make themselves known. Appointment as "representative payee" does not follow automatically. A parent is a logical "representative payee." The duties are not onerous, and it may be desirable to have an informal understanding that a sibling or other advocate will apply for this responsibility when the parent is no longer available, thus avoiding lapsing this role to a provider.

In the absence of an independent candidate whom the Social Security Administration sees as personally interested in the beneficiary, it may appoint an institution director, state agency, private proprietor or landlady to receive and administer the individual's benefits. In any case, the payee must spend the money for the benefit of the beneficiary and render an accounting from time to time to the Social Security Administration. The payee is responsible for using the beneficiary's own funds to pay any charges for care.

Most states now do not charge parents (as parents) for the full cost of institutional care, but the patient or resident (whether child or adult) is liable for that cost if personal income is available. Since Social Security benefits belong to the individual, it is legal and logical for the state to claim payment from the individual or their payee (including the parent as payee or guardian) out of the proceeds of Social Security or similar entitlement. However, the beneficiary (or payee) is entitled to retain reasonable sums for the beneficiary's personal expenses - at least \$25 a month.

The payee must keep a separate bank account in the beneficiary's name, with the payee as authorized signatory. Being a guardian or payee entails a responsibility to manage the disabled person's funds and pay the bills owed by the individual. It does not require the guardian or payee, as such, to use any personal money for the ward, a fact often not clear to prospective representative payees.

BENEFITS FOR DEPENDENTS AND SURVIVORS OF VETERANS

Veterans who are totally disabled are entitled to certain assistance and services for the benefit of their dependents in addition to Social Security for which they also receive credits while in the service. On the assumption that such veteran parents have already been advised of the current entitlements with respect to their minor children and adult disabled children, this section will be focused on those survivors benefits which can be activated on the death of the active duty member or veteran.

For the purpose of this discussion, a "survivor" will be understood to include a widow or widower, a minor child, or a child over 18 who is unmarried and has been disabled since childhood. (Note that marriage of a minor child, and remarriage of a widow or widower may affect eligibility as a survivor; provisions are not uniform for all programs.)

If a member of the armed forces or a veteran died after January 1, 1957, from a disease or injury incurred or aggravated in the line of duty while on active duty or duty training, survivors are entitled to **dependency and indemnity compensation (DIC)**. DIC consists of monthly payments based on the veterans pay grade at time of death. Survivors of veterans who die of non-service connected causes after July 1, 1960, may also receive a **death pension** if they have no significant other income.

Survivors may also be entitled to **educational assistance** for up to 45 months. In the case of a handicapped dependent, educational assistance can cover "special restorative training" and the age limits which apply to children (usually 18 to 26) may be waived. However, these benefits are limited to survivors of active duty personnel and of veterans who were totally disabled from service-connected causes when they died.

Military services career retirees may opt to take a reduced annuity for themselves in order to effectuate an annuity for a survivor. A retiree may direct the entire benefit to a dependent child even if a spouse is living.

The **Survivor Benefit Plan** for the Uniformed Services (1982 edition) is the subject of a comprehensive brochure published by the Armed Forces Information Service available for \$2.75 from the Superintendent of Documents, or from your Congressman.

Health insurance coverage is provided as a fringe benefit for active duty members and retirees of the uniformed services, i.e., the Army, Navy, Air Force, Marine Corps, Coast Guard, the Commissioned Corps of the Public Health Service and National Oceanic and Atmospheric Administration and their dependents. This program, known as CHAMPUS, includes a

broad spectrum of health care, in-patient and out-patient. In addition, CHAMPUS provides certain special benefits related to rehabilitation, institutional care and community services for mentally and physically handicapped dependents. These special benefits apply primarily to dependents of active duty personnel only, and are discontinued within one year after the parent leaves active duty, except that for a child of a member who is killed in action, payments may continue until the child reaches age 21.

Survivors of a veteran whose death was service connected or who, at the time of death, had a permanent and total service connected disability, may also have health benefits, under a law passed in 1973. Such a survivor who is not eligible for CHAMPUS and is under 65 becomes eligible for CHAMPVA, Civilian Health and Medical Program - Veterans' Administration. In-patient care for a "chronic or a nervous or mental disorder" beyond 90 days requires special approval and "domiciliary care" is excluded. A valid CHAMPVA card must be obtained. There are certain deductibles and a 25% co-insurance applied to "reasonable costs." Disabled Medicare beneficiaries who are under 65 are covered to the extent that CHAMPVA benefits are broader than Medicare. Medicare benefits must be exhausted first, as must any other health insurance which the beneficiary has. Contact any VA medical facility for further information.

BENEFITS IN-KIND

In-kind refers to goods or services having a cash value which are made available directly in lieu of the dollars to buy them. A prime example of an in-kind public benefit is food stamps, although some states provide cash rather than stamps. Another "in-kind" program that can, in some cases, make a real difference in lifestyle when combined with cash benefits under SSI or Social Security or trust income or earnings, is **rent subsidies** under Section 8 of the Housing and Community Development Act.

Section 8 is not to be confused with "Public Housing." Although there are some public "projects" in which a number

of units are reserved for Section 8 tenants, prospective tenants also may find their own apartments or units, provided they meet HUD standards for health and safety and are available at a "fair market" rental. Eligible tenants are those who, at the time they first rent the units, have adjusted annual family income not in excess of 80% of the area median income. HUD is authorized to provide payments on behalf of eligible families (including handicapped/disabled individuals) occupying newly constructed, substantially rehabilitated, or existing rental housing. The payments are made directly to the owners, making up the difference between the HUD-approved rent and the amount the tenant is required to pay. Fair market rents are established by HUD and the required payment by tenants run between 25% and 30% of the tenant's adjusted income.

It should be noted that Section 8 rental assistance payments are not considered countable income under the Supplemental Security Income program (SSI). Also, they may be paid on behalf of handicapped people who can and do work. Some communities have some barrier-free housing units available for Section 8 use.

COMBINING AND MAXIMIZING BENEFITS

Social Security benefits are based on the average prior monthly earnings from all sources on which FICA taxes have been paid on behalf of a specified insured individual. Thus they are "portable" from one job to another. A dependent may be entitled on more than one earnings record, as for example, the individual's mother or father. If so, benefits are not additive. One must be chosen. Moreover, where a parent is enrolled in some **other** social insurance system, such as a state pension plan, which is not covered by Social Security but includes adult disabled child's benefits, then benefits based on both types of covered employment either of that parent, or of both parents, may be paid concurrently. It is a legitimate strategy for at least one parent to seek "covered" employment of sufficient duration to assure insured status under Social Security on behalf of a disabled child. Also, if both parents are insured under Social Security, the resulting limits imposed by the maximum family

benefits rule may be less stringent. Moreover, a dependent who is entitled on the record of a parent who has retired, died or become disabled, may begin receiving benefits on that record even though the other parent still works. Later the child may elect to transfer to a higher entitlement when the second parent retires.

Benefits for the worker and for all dependents are permanently reduced if benefits are claimed before the worker turns 65. Thus it may be desirable to postpone claiming benefits even if one stops working at age 62. The reduction is 20% if payment begins at that age, it will be larger after the year 2,000.

Under recent legislation, the Railroad Retirement System as well as the career military retirement system are partially integrated with Social Security. Moreover, total benefits to minor and adult disabled children under these systems can exceed the maximum under Social Security. Railroad employees should check with the RRB District Office about these and other provisions of the latest legislation.

Although duplicate payments for the same service are obviously fraudulent, Medicaid, CHAMPUS, CHAMPVA and private health insurance can be used to supplement Medicare. Payments made under these programs or under social services never reduce Social Security, but under some circumstances may reduce SSI, as in the case of Medicaid payment for in-patient care lasting more than a month.

As should be clear from the earlier text, Supplemental Security Income is always reduced when combined with other regular, unearned income totaling more than \$20 per month.

Although board and lodging continue to be covered as part of in-patient care under Medicaid, maintaining one's regular living arrangement while in a hospital or nursing home for more than a month may be a problem for a person with mental retardation. This problem illustrates the need for a guardian or advocate.

WHERE TO GO FOR MORE INFORMATION

This material on governmental programs cannot do much more than alert the provident parent or counselor to those programs which are most likely to apply to the person with mental retardation for whom benefits are being applied. When a selection has been made, more detailed and updated information must be sought.

Select the publications most applicable to your situation from the "For Further Reading" section at the end of this pamphlet. Among the publications listed, the **Social Security Handbook** is especially recommended for anyone counseling parents, and for parents themselves who wish to delve deeper into the subject. It is well indexed and covers not only Social Security, but SSI, Medicare, Railroad Retirement and a variety of details and anomalies impossible to deal with in this booklet. The coverage of the other publications is indicated by their titles. They are recommended for those persons to whom they primarily apply. The various short pamphlets on Social Security are too numerous to list. A visit to your district office will enable you to select those most pertinent to your situation.

It is the duty of the local Social Security District Office not only to advise inquirers concerning Social Security and SSI but also to refer applicants to the appropriate health and social agencies within the state. The Social Security District Offices are now listed in the phone books under **Social Security** (not U.S. Government), but the local address listing may be missing from small town books. In this case, inquire at your local Post Office. Such Post Offices usually have information about "contact points" - that is, the places and times when a Social Security representative will visit your community. You can also use **TeleService**. Look for the toll free number under **Social Security** in the phone book. The Social Security Administration encourages you to do business by phone, preferably after mid-month unless the matter is urgent. (If you are calling about a check or claim, be sure to have your claim number or Medicare card, or a recent notice in hand.) The Post Office will also have the phone number and address of the Social Security and Railroad Retirement District Offices serving your area.

TO SUMMARIZE

You have many factors to consider in providing life-time protection for your child with mental retardation. You should consider obtaining a judicial determination of the need of a court appointed guardian shortly before or soon after your child reaches the age of 18; a guardian should be appointed for anyone found to be legally incompetent. Not all persons with mental retardation need guardians, however.

It is vital that you prepare a will upon the advice of a competent attorney. Your will may create a trust that will make proper specific financial provisions for each of your children, including your child with retardation, or you may create a living trust before you die. In any case, you should review your will about every five years or when circumstances change significantly.

Life insurance on your life is recommended; the proceeds from it can enlarge your estate or trust and increase the protection of your children. In planning both your life insurance and your total estate, you will not want to forget the benefits available to your survivors under the Social Security Act and the other governmental programs described here, as well as under one or more of the ARC insurance programs. Visit your local Social Security Office and review the various pamphlets on display.

Keep in mind that the various factors affecting your future plans for your child are changing in response to policy changes as well as the child's personal development and status. These factors are interrelated and must be considered in an entire, overall, single picture. The prospects should be reviewed in their entirety from time to time.

Plan now to avoid future complications and heartache. Review and revise your plans periodically.

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FOR FURTHER READING

Government Bulletins

Single Copies of most of the following publications are available free from the district or central offices of the respective agencies or from your Congressman. The most popular are also available in Spanish. Those with a price noted may be ordered from **The Superintendent of Documents, Washington, D.C. 20402.**

If you cannot locate a local office of the relevant government agency by looking in the telephone book or asking at the Post Office, you can reach the national headquarters as follows:

**U.S. Civil Service Commission
Washington, D.C. 20415**

**U.S. Dept. of Health and Human Services
Social Security Administration
Health Care Financing Administration
Washington, D.C. 20201**

or

Baltimore, Maryland 21235

**U.S. Department of Housing & Urban
Development
Washington, D.C. 20410**

**U.S. Railroad Retirement Board
Chicago, Illinois 60611**

**U.S. Veterans' Administration
Information Service
Washington, D.C. 20420**

From the U.S. Civil Service Commission, Bureau of Retirement, Insurance and Occupational Health:

- *Your Retirement System – Questions & Answers
Concerning the Federal Civil Service Retirement Law*

From the Social Security Administration:

- *A Guide to Supplemental Security Income*
- *A Woman's Guide to Social Security*
- *Applying for a Social Security Number*
- *1980 Changes in Social Security & SSI
Disability Protections*
- *Estimating Your Social Security Retirement Check*
- *Filing for Social Security or Supplemental Security
Income Disability Benefits*
- *How Work Affects Your Social Security Checks*
- *If You Become Disabled*
- *Reporting Changes that Affect Your Gold SSI Checks*
- *SSI for Aged, Disabled and Blind People*
- *SSI for Aged, Disabled and Blind People in (your state)*
- *Social Security Handbook (7th Edition) [DHEW No.
(SSA)05-10135/Price: \$7.50]*
- *Social Security Strengthened
1983 Social Security Amendments*
- *Thinking About Retiring?*
- *Your Duties as a Representative Payee*
- *Your Right to Question the Decision Made on Your
Social Security Claim*
- *Your Social Security*
- *Your Social Security Checks While You are Outside
the United States*
- *Your Social Security Rights & Responsibilities
Disability Benefits*

From the Health Care Financing Administration

- *A Brief Explanation of Medicare*
- *A Guide to Health Insurance for People with Medicare*
- *Recent Changes in Medicare*
- *Your Medicare Handbook*

From the U.S. Department of Housing and Urban Urban Development:

- *HUD Programs That Can Help the Handicapped*

From the U.S. Railroad Retirement Board:

- *Important Facts About RRA Survivor Benefits and
How They Can be Obtained*
- *Railroad Retirement and Survivor Benefits for
Railroad Workers and Their Families*
- *Your Duties as a Representative Payee*

From the Veterans' Administration:

- *CHAMPVA – VA Health Benefits Services for
Dependents and Survivors*
- *Federal Benefits for Veterans and Dependents (or from
Superintendent of Documents for \$4.50)*

The following are published for members of all the U.S. Uniformed Services by the American Forces Information Service (Defense Department), but are not distributed by them. Persons on active duty can obtain copies through their Command or Service Publication Center; otherwise, from the Superintendent of Documents (at prices given):

- **Once a Veteran (\$4.75)**
- **Survivor Benefit Plan for the Uniformed Services (\$2.75)**

BACKGROUND MATERIAL FOR PARENTS AND THEIR ATTORNEYS

A NEW LOOK AT GUARDIANSHIP ● PROTECTIVE SERVICES THAT SUPPORT PERSONALIZED LIVING. Apolloni, T. & Cooke, T.P. Paul H. Brookes Publishing Co., Baltimore, Maryland. 1984 (\$24.95)

ALTERNATIVES - A FAMILY GUIDE TO LEGAL AND FINANCIAL PLANNING FOR THE DISABLED. Russell, M. First Publications, P.O. Box 1832, Evanston, Illinois 60204. 1983. (\$9.95 + \$2 shipping & handling)

CONSENT HANDBOOK. American Association on Mental Deficiency, 5101 Wisconsin Ave., Washington, D.C. 20016. 1977. (\$4.40)

DISABLED PERSONS AND THE LAW - STATE LEGISLATIVE ISSUES. Powell, D., Sales, R. VanDuizend and Associates. Plenum Press, New York. 1982 (\$75)

MEDICARE SUPPLEMENT INSURANCE. *Consumer Reports.* June, 1984. pp 347-355

PRACTICE MANUAL FOR SOCIAL SECURITY CLAIMS + 1983 SUPPLEMENT. Practising Law Institute, 810 7th Ave., New York 10019. (\$40)

THE RIGHTS OF MENTALLY RETARDED PERSONS. Friedman, P. Avon Books, Mail Order Department, 250 W. 99th St., New York 10019 (paperback). 1976. (\$1.50 + 25¢ shipping & handling)

SECURING THE LEGAL RIGHTS OF RETARDED PERSONS. Ogg, E. Public Affairs Pamphlet #492, 381 Park Ave., South, New York 10016. (35¢)

SOCIAL SECURITY DISABILITY CLAIMS COURSE HANDBOOK. Practicing Law Institute, 810 7th Ave., New York 10019. 1984. (\$35)

WILLS AND TRUSTS - A LEGAL AND FINANCIAL HANDBOOK FOR EVERYONE. Hemphill, Jr., C. Prentice-Hall, Inc., Englewood Cliffs, New Jersey 07632. 1980. (\$7.95)



Association for Retarded Citizens

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